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Self-Direction in Medicaid: Challenges & Opportunities

United Healthcare

Introduction

Long-term services and supports (LTSS) refers to a broad range of medical, functional and social services that are needed by individuals who have complex health needs due to aging, chronic illness or disability.

Types of individuals who need LTSS

Elderly, ages 65+

Non-elderly adults with physical disabilities or intellectual and/or developmental disabilities (I/DD), ages 16–64

Children with physical disabilities or I/DD, under 18

The need for LTSS affects individuals of all ages and is generally measured by limitations in one's ability to perform activities of daily living such as eating, bathing, dressing or walking, and activities that allow individuals to live independently in the community, including shopping, housework and meal preparation.[1] LTSS are delivered in a variety of settings, including home- and community-based settings (e.g., adult day services and personal care/homemaker services) and institutional care (e.g., intermediate care facilities for people with intellectual and developmental disabilities and nursing homes).

For many who utilize LTSS, living independently and the opportunity to self-direct needed services are central to their personal satisfaction. For these individuals, home- and community-based services (e.g., adult day services and personal care/homemaker services) are crucial.

Independent living and self-direction are often misunderstood, which can compromise a person's experience. This paper seeks to provide a glimpse into the dynamics of self-direction, along with some of the challenges people experience when attempting to leverage self-direction services.

Overview: Defining Self-Direction and Who It Serves

Self-direction is a service delivery option within Medicaid HCBS programs that is known by many names (e.g., self-direction, consumer direction, participant direction). The core idea surrounding self-direction is the belief that individuals of all ages and those living with all types of disabilities have the right and ability to assess their own needs, determine the caregiver who can meet those needs, and evaluate the quality of services provided; ultimately, self-direction is about individual empowerment and the ability to actively make choices. More formally, self-direction got its start in the mid-1990s with grants awarded by the Robert Wood Johnson Foundation. That work led to demonstration projects and, eventually, the use of self-direction in state plan and waiver services, with parameters defined by the Centers for Medicare & Medicaid Services (CMS).[2]

While details vary from state to state, self-direction programs are required to provide a person-centered approach for an individual that allows for their needs to be identified and services managed.[3] For individuals utilizing assistive services at home, the services provided are often highly personal in nature and the provider of those services needs to be a trusted resource. Through self-direction, people are able to maintain their autonomy and dignity by empowering them to make choices about when, how and who delivers the services.

In Medicaid, eligibility to leverage self-direction depends on each state's defined use of self-direction for groups that utilize home- and community-based services. Generally, these waivers cover:

- Older adults and those of all ages with disabilities
- Individuals for whom a designated representative assists with decision-making to support self-direction

The Mechanics of Self-Direction[4, 5, 6]

Understanding how self-direction is operationalized requires an understanding of the delivery of long-term services and supports (LTSS) in Medicaid. Medicaid is the largest payer of LTSS (a combination of services delivered in the community and/or in an institution), with home- and community-based services (HCBS) making up more than 57% of the annual Medicaid expenditure.[7] HCBS are enabled through various waivers. The Centers for Medicare & Medicaid Services (CMS) allows latitude with the implementation of their waivers but requires that all States permit some type of self-direction as part of their waiver structure; these details are outlined below.




Waiver Type	Targeted To	Self-Direction Services	Additional Info
1915 (c)	Medicaid eligible population	Optional	
1915 (i)	Specific populations outside of standard Medicaid eligibility	Optional	
1915 (j)	Self-directed personal assistant services	Included (standalone waiver)	Must be accompanied by 1915 (c)
1915 (k)	Community First Choice	Automatically included	Includes 6% increased FMAP

CMS also has some basic guidelines that apply across all self-direction opportunities:

Option to select self-direction: A state must allow individuals to opt in or out of self-direction. If individuals do not wish to self-direct, the state must offer a "provider managed" service delivery option concurrent to the self-direction option.

Person-centered planning process: Each individual leveraging self-direction services must undergo an assessment to determine the level of need and services required. Based on the assessment, a person-centered plan is developed. Development of the plan must be directed by the individual who will receive services, with assistance as needed provided by the person of the individual's choosing. The developed plan must also include planning for contingencies such as when a needed service is not provided due to the worker being out sick. The final, written document is known as a service plan.

Financial Management Services (FMS): States are required to make FMS available to individuals who are self-directing. Individuals can perform some or all of the FMS for themselves, but many prefer the assistance of an FMS entity for a variety of payroll and budget monitoring tasks.

Quality assurance and improvement: State Medicaid agencies are required to have in place a system of continuous quality assurance and improvement (QA & I) for self-direction. While these systems vary from state to state, they are generally similar to an individual state's other Medicaid QA & I processes, and include ongoing monitoring, reporting, issue remediation and opportunity identification.

Consumer Challenges to Engage in Self-Direction

One of the leading challenges that consumers face regarding self-direction is lack of awareness or understanding of the programs available. People who utilize LTSS services covered by Medicaid in a fee-for-service environment are often unaware of their opportunity to self-direct or are unsure how to begin self-directing. While many education tools exist, they are often buried within state Medicaid websites or are limited regarding how and where to get started. Highlighting self-direction information on websites, making materials accessible, and developing easy-to-follow tutorials for pursuing self-direction can open doors to useful conversations. By helping consumers understand their option to self-direct and providing actionable information on how to get started in self-direction, LTSS services can empower consumers to take control of the care-receiving journey.

Another common challenge from consumers who want to self-direct is how to find a reliable and appropriately skilled caregiver. Continuity of consistent care is critical to consumers who self-direct, making the tools used to locate available caregivers a top concern. Reliable and consistent caregivers can mean the difference between getting out of bed, bathed, dressed, and eating or being bed-bound and unable to accomplish these things. Many states do not typically allow consumers to hire an immediate family member, and websites designed to assist in the search for outside-the-home caregivers are often outdated and can be difficult to navigate. These challenges can create distrust and confusion. While consumers know their needs better than anyone else, when they are unable to hire the people who can provide safe and appropriate care, the idea of self-direction fails and is often abandoned. Creating access to skilled caregivers by allowing family members to be paid caregivers, increasing training opportunities for caregivers, and regular maintenance of caregiver websites would significantly impact the ability of individuals to actively leverage self-direction opportunities.

State Approaches to Improving Adoption and Effectiveness of Self-Direction

State health and Medicaid departments are often managing heavy workloads and are stretched thin — limiting their capacity and time to engage with beneficiaries. State-based case managers available to support self-direction can also be limited. States who contract with MCOs are better situated to encourage self-direction as the MCO care managers are trained to introduce the option of self-direction and support the consumer's choice. Leveraging MCOs for LTSS services allows states to employ additional tools to increase adoption of self-direction services while reducing additional administrative burden on existing staff.

Fraud, waste and abuse are ongoing concerns in Medicaid and are particularly relevant when strangers will be charged with the care of another, as is the case with self-direction. While research shows that fraud is not prevalent in self-direction and is no more likely to occur than in an agency model, it is important for stakeholders to remain aware.[8] In fee-for-service-based self-direction, states often know little about the caregivers that have been engaged and, because consumers are directly in charge of their services, states lack the regulatory oversight they may have in an agency model. States seek to address this need for oversight by implementing consumer protections, including disallowing payments when a consumer is hospitalized, partnering with fiscal intermediaries to exchange data, and requiring every caregiver to register with the state as a provider.[9] Leveraging MCOs can also improve the vetting and oversight process through consistent contact with the consumer and strong partnerships with FMS providers.

As with anyone who hires another to provide help at home, individuals leveraging self-direction services need to be fully informed about the people welcomed into their home, and these approaches to consumer protections help ensure that hired caregivers act in the best interests of the individual and are held accountable for maintaining safe, professional environments and services.

Self-Direction Within Managed Care

For individuals enrolled in a managed care plan for their LTSS services, the path to self-direction can be a well-supported one. In a managed care environment, a case manager is one of the supports available to a person who wishes to self-direct. The case manager can help the individual with understanding the options available for self-direction, identifying the services needed, supporting the selection and training of caregivers, and finding and suggesting other tools to help with independence.

Amanda is 19 years old and has Down syndrome. She recently graduated from high school where she had a school counselor and extra support services. Now that these services are no longer available, Amanda and her family caregivers are uncertain of her options.

Fee-for-Service	Managed Care
Amanda has a desire to live independently, but requires some caregiving and is unsure where to find or hire a caregiver	A care coordinator helps Amanda understand and navigate the resources available to her, including hiring of a caregiver
Amanda is unsure about what the future holds and how to handle health challenges that may prevent her from living independently	Amanda works with her care coordinator, doctors and caregiver to help develop a plan that prepares her for living independently
Amanda does not know where to gain experience or training that can help her live independently in the future	Amanda joins an internship program to gain work experience and enrolls at a local community college through their supportive programming

The Role of Managed Care in Increasing Self-Direction Utilization

The primary aim of MCOs is to ensure that members are appropriately utilizing all services for which they are eligible. In the context of individuals who require LTSS, this includes creating a person-centered care plan and supporting member choice, which includes access to the opportunity to self-direct services. Some consumers have never heard of self-direction, and others who have are afraid they will be on their own to find a caregiver.

MCOs serve an important role in educating consumers on the benefits, the opportunity of self-direction, and their responsibilities if they opt to self-direct. MCOs can also reassure consumers that they will be supported in their self-direction journey, including assistance with locating the right caregiver and helping to decide when self-direction services are not the right fit. Importantly, MCOs can help reassure consumers that self-direction does not have to be a forever choice. A consumer can choose to try self-directing and go back to an agency model when and if self-direction is not an appropriate option.

The most critical role an MCO can play for consumers in self-direction is that of a supportive advisor. Self-direction is about choice and giving consumers the power to decide how, when and where they will receive services. An MCO's staff is trained to help consumers envision success on the self-direction path and get started on that journey.

Opportunities for Policy Reform

State limits on self-direction

Current scenario: While all states allow at least some part of the LTSS population to use consumer direction, use of self-direction and who can be paid to provide services is often limited. Populations that can leverage self-direction vary by state, as does who can be paid to provide care — some states prohibit a spouse or parent to be the paid caregiver or limit the spouse/parent to paid caregiving in only some circumstances.[10]

Opportunities for policy improvement:

- Dedicate and train staff to educate consumers about the opportunity for self-direction and guide the consumer on the path of implementing if desired.
- Advocate for states to use all appropriate funding authorities to permit broad use of self-direction across all LTSS utilizing populations.
- Allow the paid caregiver to be any individual of the consumer's choice who is able to safely and effectively provide all services for the consumer with appropriate reporting measures in place.

Equity in self-direction

Current scenario: Given Medicaid's complex eligibility, application and redetermination processes, the system can be easily overwhelming. Medicaid, as a program, can unintentionally raise equity issues given that some individuals lack the resources to get started and do not have a family member or friend who can help them navigate. Equity for people living with disabilities is even more challenging because the program requirement of limited income combined with inadequate access to necessary supports and services can make navigation seem impossible. Those who wish to self-direct may not have a friend or family member who is comfortable serving as a caregiver, or who is willing to help/learn/navigate Medicaid or the need for supports and services.

Opportunities for policy improvement:

- Remove the individual's burden by streamlining and simplifying the application process to create a fully accessible process — opening doors to Medicaid as a whole.
- Simplify self-direction tools and make those tools easy to locate — furthering access to Medicaid and the programs meant to help consumers live the life of their choosing.

Appropriate training for caregivers

Current scenario: Some states require caregivers who provide services through self-direction to have the same training as agency caregivers, which does not align with the goals of self-direction or the idea that a consumer will directly train their caregiver (e.g., the direct caregiver providing services to one person does not need to be skilled in driving a 20-passenger van, as an agency caregiver would need to be). In addition to training challenges, caregivers often need to navigate electronic visit verification (EVV) systems without the support of technical assistance. Caregivers working in self-direction are also on their own for completing the significant amount of paperwork required when applying to be a caregiver. The combination of these forces leads to caregivers leaving the self-direction space in order to reduce their own administrative burdens.

Opportunities for improvement:

- Advocate for more reasonably appropriate training requirements (such as CPR certification) and empower consumers to provide needs-appropriate training.
- Create training programs that provide skills necessary for safely caring for higher acuity consumers (e.g., safe transfers, bed sore prevention) and make that training easily searchable for consumers.
- Develop simplified EVV systems that meet the goals of EVV legislation but do not create undue burden for the consumer or caregiver.
- Simplify the pathway to employment in self-direction to encourage more caregivers to accept direct employment opportunities.

Sources:

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